DOCUMENT RESUME

ED 244 179 CG 017 451

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TITLE Measuring the Impact of a Community Workshop on Family Caregivers.
INSTITUTION Kansas Univ., Lawrence. Long-Term Care Gerontology Center.
SPONS AGENCY Administration on Aging (DHHS), Washington, D.C.
PUB DATE Nov 83
GRANT AOA-90-AT-2154/03
NOTE 25p.; Paper presented at the Annual Scientific Meeting of the Gerontological Society (36th, San Francisco, CA, November 17-22, 1983).
PUB TYPE Reports - Research/Technical (143) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Adults; Aging (Individuals); Aging Education; Control Groups; Coping; Older Adults; Outreach Programs; Pretests Posttests; *Program Effectiveness; *Program Evaluation; *Research Methodology; Social Support Groups
IDENTIFIERS Adult Children; Caregivers

ABSTRACT

Although informal assessments of caregiver training and support groups have been positive, empirical evidence of their beneficial impact is needed. To evaluate a group program for families of elderly parents, a pre/postmeasure, experimental/control group design was implemented. Adults participating in two workshops on "Your Aging Parents" were assigned to either an experimental (N=16) or a control (N=16) group. All participants completed pre-test measures, including goal statements and 20 items from the 29-item Burden Interview (Zarit, et al., 1980). Post-test questionnaires on the workshop's effectiveness were administered to the experimental group at the end of a 10-hour workshop; at the start of their workshop control group members again completed the Burden Interview. Analysis of results showed that significant differences between groups were found on only three items of the Burden Interview; experimental subjects changed in a positive direction in their feelings of usefulness and contribution, and in feelings about parents' manipulation. Program completers showed no significant change for total burden score. However, participants' ratings of program value and quality were high, and most felt they had achieved their main goals. To empirically evaluate program effectiveness, future research must focus more specifically on the development and administration of a valid and reliable instrument to measure change without disrupting the group process. (MCF)

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MEASURING THE IMPACT OF A COMMUNITY WORKSHOP ON FAMILY CAREGIVERS

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Presented at the annual meeting of the Gerontological Society of America, November, 1983, San Francisco.

Funding for this project was provided by a sub-grant from Grant #90AT2154/03 to the University of Kansas Long-Term Care Gerontology Center from the Administration on Aging.

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TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

MEASURING THE IMPACT OF COMMUNITY WORKSHOP ON FAMILY CAREGIVERS

Research has documented that adult children are the primary source of support and caregiving to the elderly (Shanas, 1979; Sussman, 1976; Troll, Miller, & Atchley, 1979). While these adult children feel a responsibility to meet the needs of their elderly parents, many also feel frustration or even desperation at the constraints on their lifestyle brought about by their parents' needs (Robinson & Thurnher, 1979; Schmidt, 1980). Frequently the middle aged feel "sandwiched" between their aging parents and their children -- just as they have raised their own children, they have to take care of their parents (Brody, 1981; Brody, 1978; Neugarten, 1979). Dealing with increased dependency needs of parents can be a source of considerable stress, yet adult children accept the responsibility, often at great cost to themselves. Problems associated with the burdens of caring for elderly parents can be expected to increase as the ratio of older persons to younger increases, and as government services for the elderly are curtailed.

If the informal support network is to continue to provide extensive care for the elderly in our society, it is important to consider the needs of the caregivers as well as the services they can provide. In a recent review of the literature on family and friends as caregivers, Sonberg and Emrich (1982) point out that support to the informal support network must go beyond financial incentives. They state: "If family and friends are seen as the service providers of choice, support for the supports must also

come in the form of training. This implies a broadening of the concept of the 'aging network' and a realignment of efforts within the gerontology and geriatrics education establishment."(p.1) Similarly, Brody (1981) warns against a "tunnel vision focus" that looks only at the needs of the elderly, and overlooks the needs of the family. Such a focus serves neither generation well, since the well-being of the generations is interlocked.

If we in gerontology are to provide such training to the informal support system, we must be concerned with the demonstrable impact of the training. This is important not only so that we can provide programs that will actually help caregivers, but also because with current emphasis on accountability, funds for providing such programs are difficult to obtain unless we can demonstrate beneficial impact. It seems probable that programs designed to provide adult children with information about the aging process and about community resources available to the family, as well as the opportunity to openly express their feelings and concerns, would relieve some of the pressure and assist them in their caregiving role. In recent years such programs have been developed: in some cases for specific populations such as relatives of alzheimer patients (Lazurus, et.al.,1981), of aphasic patients (Bardach, 1969), or of the institutionalized aged (Lewis, 1980; Smith, Lelong and Adelberg, 1981); other programs are more generally directed to all those concerned with aged parents (Goodman, 1980;Silvermann, Drahce,& Zielinski,1981). In addition, numerous self-help books are available as guides for relatives of elderly persons (see for

example, Mace and Robins, 1981; Schwartz, 1977; Silverstone and Hyman, 1982).

Such programs and materials intuitively appear to be addressing the problem, and instructors' observations as well as participants' reports corroborate this perception. However, very little formal evaluation of such programs has been reported, and what has been reported lacks the statistical evidence required to demonstrate impact. For example, Safford (1980) in her description of a 3-year educational and support program for families of the mentally impaired aged, reported "demonstrated benefits for participants." However, the evidence she gives for these benefits consists of describing the activities of the participants and discussing the long term support group which grew out of the program. A pilot study of a group for relatives of Alzheimer patients reported by Lazarus et.al.(1981) found that relatives who attended eight or more of the ten weekly meetings felt significantly more in control of their lives and less at the mercy of fate (as measured by Rotter's [1966] locus of control) than they did prior to the group, while relatives not participating in the discussion group showed no significant change. Unfortunately, it is difficult to generalize from these results since the experimental group contained only 4 members (those relatives who chose to participate in the discussion group) and the control group only 3 members (those who chose not to participate).

Hartford and Parsons (1982) have reported on an 8-session group approach for relatives of dependent older adults, which

resulted in some change for a few individuals in the group (as measured by the Ontario Attitude Test), but no definitive change for the group as a whole. They state that, "Probably the most important outcome of the experience was that members appeared to function better and reported that they had a better grasp on their situation and had found some relief in sharing with others."(p.398). Similar informal outcomes of education and support groups for families of the aged that have been reported include reduction of feelings of guilt and anxiety, experience of emotional support, increased sense of being able to cope, exchange of practical day-to-day management techniques, and increased knowledge of the aging process (Bardach, 1969; Lewis, 1980; Safford,1980; Smith,et.al.,1981; Lazurus,et.al.,1981; Hartford & Parsons,1982).

We do not intend here to devalue our colleagues' attempts to evaluate their programs. In fact we are impressed with the highly positive tone of their informal assessments and clinical impressions. Our concern is with providing more conclusive evidence for the value of such programs, particularly evidence involving comparisons with comparable control groups. In an attempt to collect such data we developed a project designed to evaluate a group program for families of elderly parents using both pre-group, post-group measures and an experimental group/control group design. Two four-week workshops entitled, "Your Aging Parents" were advertised throughout the community by means of brochures, newspapers, and radio. The first series was offered on four consecutive Tuesday evenings; the second series began the week after the first series ended and was offered for

four Monday evenings. Participants selected either the Monday or the Tuesday series, but all were asked to register before the first series began. Thus pre-test data could be initially collected from both groups, and the second group could serve as a control group during the period of the first workshop.

Measures

All participants were mailed an informed consent statement and a written questionnaire to complete and return before the workshops began. This pre-test questionnaire included demographic data on the participants and their parents, twenty items from the 29-item Burden Interview designed by Zarit et.al. (1980) to assess caregivers' feelings of burden, and two questions designed to elicit participants' primary goals for the workshop . The Burden Interview was used because Zarit et.al.'s 1980 study of correlates of caregivers' feelings of burden suggested that an intervention program providing such support to caregivers might be effective in reducing feelings of burden.

Participants in the first four-week series constituted the experimental group. During the final session of their workshop series they completed a post-test questionnaire which included six items on which they assessed their feelings of having developed useful skills as a result of the workshop, five items on which they rated the quality of the workshop, and the 20-item Burden Scale from the pre-test.

Participants in the second four-week series constituted the

control group since they received no treatment during the time period of the first workshop series. At the beginning of the first session of their workshop this group completed the Burden Interview again, which served as a post-test for purposes of comparing changes in feelings of burden between the two groups. During the final session of their workshop series they also completed the same post-test questionnaire used in the final session of the experimental group, in order that the effectiveness of the workshop for this group of participants could also be ascertained.

Composition of Groups

A limit of 20 participants was imposed for each workshop series in order to allow for group discussion. Each series was filled, and we had a waiting list of 10 additional people. Although each group contained 20 people, complete sets of data were obtained for only 16 participants in each group. (Data were not used for any participant who missed more than one of the four sessions. Also, some data were discarded because participants did not send in their pre-tests soon enough.) Therefore, reports of group characteristics and results will include only these 32 participants. Characteristics of the 32 participants and their parents are provided in Tables 1 and 2.

Goals of the Participants

Two questions were asked on the pre-test to elicit participants' primary goals for the program: (1)"If the workshop is going to be a good program for you, what is one question you'd want

answered?", and (2) "What would you most like to get from this workshop?". The five main categories of goals in order of decreasing prevalence were the following: (1) learning how to help parents; (2) developing knowledge and understanding of the aging process and its problems; (3) improving relationships with parents and/or coping with changes in these relationships; (4) sharing problems and getting support from others facing similar concerns; and (5) dealing with one's own feelings of guilt, frustration, etc.

The majority of goals listed (63%) fell into the first two categories, which dealt primarily with acquiring knowledge -- about the aging process, about problems of aging, and about how to help parents deal with aging. Thirty-seven percent of goals listed fell into the category of learning how to help parents. These included such goals as finding out what community resources are available to help elderly parents, assisting parents in making decisions about living arrangements, and helping parents make the remainder of their lives as fulfilling as possible. Twenty-six percent of goals listed were in the category of developing knowledge and understanding of the aging process and its problems. Examples are developing a better understanding of the physical and emotional changes that come with age, learning to anticipate and plan for possible illnesses of parents, and understanding senility.

The remaining 37% of goals listed fell into the last three categories, which dealt primarily with feelings. Participants were concerned about avoiding assuming the parent role from their parents, setting limits to their parents' demands, discussing problems with their parents, and coping with their own feelings of depression, anger, or

guilt regarding their parents. They also wanted to see how others deal with their aging parents, to share their concerns over parents' welfare with others faced with similar problems, and to get some idea of whether they were doing things as well as they could.

Content of the Workshops

Each of the four two and one-half hour sessions was a combination of short lectures, audio-visual presentations, and group discussion. Handouts expanding on the topics discussed were provided at the end of each session. In addition, readings were suggested from the book, You and Your Aging Parents (Silverstone and Hyman, 1982) which was provided to all participants. The sessions focused on the following topic areas: (I) Intergenerational communication: dealing with family conflict; (II) Physical and psychological processes of aging; (III) Community resources: availability and use; (IV) Decision making, living arrangements and lifestyle.

Evaluation of Effectiveness

Significant differences between the experimental and the control groups in terms of pre-test/post-test change were found for only three items on the Burden Interview. Participants in the experimental group changed in a positive direction on the following items: (5) "I feel that I don't do as much for my parent as I could or should"; (11) "I feel that I am contributing to the well-being of my parent"; and (20) "I feel that my parent tries to manipulate me". Participants in the control group changed in a negative direction on these items. A number of other

differences between the two groups followed this pattern, but did not provide significant results (see table 3).

Comparisons of pre-test/post-test scores for all participants after completing the program showed no significant change for total Burden Score, although there was a decrease after the workshop (see table 3). Significant change was found on only one of the 20 individual items: participants were significantly less likely to feel their parents were trying to manipulate them after completing the workshop than they were before (see table 3).

Our less formal evaluations were quite positive, similar to those our colleagues have reported in the literature. On a 7-point scale (where 1="not at all" and 7="very much"), the Mean rating of all participants completing the post-questionnaire (N=32) for "I feel that I have achieved the main goal I had for this workshop" was 5.6. Furthermore, 20 of the 32 participants gave ratings of 6 or 7 for this item, while only 2 gave ratings below 4. Other evaluative items showed similar results. For example, the Mean rating for "As a result of this workshop, I feel more confident that I can help my aging parent", was 5.3; and for "As a result of this workshop, I feel more capable of helping my parent make use of community resources", it was 5.8 (see table 4).

Our clinical impressions were that participants showed progress in dealing with important issues and conflicts, and felt significant support from realizing that others in the group shared their feelings of guilt, frustration and anxiety. Attendance was high, with an average of 18 attending each

session. Participants repeatedly told us that they found the program valuable and would like to have more such programs. Their overall rating of the quality of the program (on a 5-point scale, where 1=very high, and 5=very low) was 1.6, and their overall desire to attend a more advanced workshop on this topic was 2.2 (see table 5). Of the 40 participants in the two workshops, 17 signed up to participate in an on-going support group to begin after the second workshop ended.

The following are some written comments from participants describing what they found most useful about the workshop. "It helped me to realize others are dealing with similar problems, or more severe ones." "Practical suggestions were offered by a number of individuals in the group." "I understand better the personal feelings of the elderly." "I broadened my perceptions about what my parents may be experiencing as they age." "I am coming away with the knowledge that there <u>are</u> services available, not only for aging parents, but also for worrying children." "The information on obtaining help, getting transportation, etc. was very helpful." "The program is great & helped me to accept my parents for themselves, to learn to assert myself to them and to know how to get help for them when the time comes." "The videotapes were very 'eye opening' and helpful for me, as was the information about the things available in our area to help people stay independent and happy in their own homes." "Previously I had very limited information on the problems of aging and available solutions. It was valuable to learn of the experiences of others." "I liked the fact that it was well-rounded, touching

on a variety of topics rather than focusing only on the emotional or only the physical aspects."

Discussion

Obviously we did not succeed in providing a strong empirical demonstration of the value of this program for families. Nevertheless, the less formal assessments have convinced us of its value, as was the case in similar projects reported in the gerontological literature. We should point out that our program differed somewhat from these others in that many of our participants did not have parents who were dependent. These participants did not need specific help at this time, but were preparing for the future. Although they reported that they benefited from the program, the real assessment of its value to them probably cannot be made until they are in a position of needing to provide more support to their parents.

The fact that the majority of the goals participants listed for the workshop dealt primarily with acquiring knowledge (63%) as compared to those which dealt primarily with feelings (37%), may partially account for the discrepancy between the participants' ratings of the workshop and the pre-test/post-test change results. Since 3 of the 6 ratings questions asked participants to evaluate how much they felt they learned that would enable them to help their parents, while only 2 questions asked about improvement in relationships, with the remaining question asking whether they had achieved their main goal, the primary focus of these ratings for these participants is on knowledge acquired. The Burden Interview, on the other hand, focuses primarily on feelings and relationships. If participants

primarily wanted knowledge and information and felt they acquired it, this would account for their high overall ratings of the workshop.

Perhaps change in areas measured by items in the Burden Interview cannot be assessed over such a short period, or perhaps a more extensive intervention is required to produce such change. The one item that did show significant pre/post change for the combined groups, "I feel that my parent tries to manipulate me", is interesting. Possibly as participants learned more about aging they felt more empathy for their parents' problems and needs, and understood better some of their parents' requests.

The significant differences between the experimental group and the control group on the items, "I feel that I don't do as much for my parent as I could or should", and "I feel that I am contributing to the well-being of my parent", would indicate that the workshop helped participants to feel better about the way they were meeting their responsibilities to their parents. However, the significant differences were also due to the fact that the control group changed in a negative direction on these items, which is more difficult to explain. Similarly, the differences in total Burden Score between the two groups followed this pattern of the experimental group improving while the control group became worse. While this difference did not reach significance ($p=.112$), given that the groups were so small ($N=16$ for each), the difference is large enough to be interesting.

As we consider the problem of evaluating this and similar programs, we are confronted with difficult issues. Should we

simply accept the informal evidence and assume such programs provide valuable support to caregivers, or should we continue our attempts to demonstrate their value? A number of the researchers mentioned earlier in this paper have suggested that more conclusive evidence would be desirable. For example, Lazurus, et.al. conclude their report by stating that, "A study which utilizes a larger population with random assignment of relatives to the experimental and control group would reduce the number of confounding variables"(p.357). Also, Zarit, et.al. point out that while one implication of their findings is that an intervention program that increases informal social supports may be effective in reducing feelings of burden; and while various types of professional interventions are available, including support and educational groups; research measuring the supportive impact of their intervention on caregivers is lacking.

It seems however that the present research has demonstrated that conducting a carefully controlled study using experimental procedure is not all that is needed. If we are to demonstrate change, a valid and reliable instrument which can be easily administered without disrupting the group process must be developed or discovered. Those instruments used in studies reported so far do not appear to be sufficiently sensitive to show the change, if it is indeed occurring. Perhaps we need long-term follow-up to allow us to measure change as people incorporate what they have learned into their situations, although such follow-up is time consuming and costly. Perhaps we should rely on intensive case studies to provide us information, even though it is difficult to generalize from such data.

It seems that we who provide such programs and believe in them must confront these issues. If we truly are convinced of the value of these programs for families, we will want to provide them on a wide scale and inexpensively. This will require external funds, which increasingly requires empirical demonstrations of beneficial impact.

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Table 1: Characteristics of Participants in Group 1

Sex of Participants: F=14, M=2

Age of Participants:

<25	1(6.3%)
26-35	4(25%)
36-45	4(25%)
46-55	6(37.5%)
56-65	1(6.3%)
>65	0

Mother's Age: M=71.9 Range = 56-91 N=15

Mother's Residence:

Same Community	= 6(40%)
Other Communities in State	= 4(26.7%)
Out-of-State	= 5(33.3%)

Mother's Living Arrangements:

Own home or apt. with spouse	= 10(66.7%)
Own home or apt., alone	= 3(20.0%)
With me	= 1(6.7%)
Nursing home	= 1(6.7%)
With other relative	= 0
Own home with full-time care	= 0

Father's Age: M=72.9% Range = 61-91 N=11

Father's Residence:

Same Community	= 6(54.5%)
Other Communities in State	= 2(18.2%)
Out-of-State	= 3(27.3%)

Father's Living Arrangements:

Own home or apt. with spouse	= 9(81.8%)
Own home or apt., alone	= 0
With me	= 2(18.2%)
Nursing home	= 0
With other relative	= 0
Own home with full-time care	= 0

Number of Surviving Parents:

Both Parents	= 10
Mother Only	= 5
Father Only	= 1

Table 2: Characteristics of Participants in Group 2

Sex of Participants: F=13, M=3

Age of Participants:

<25	1(6.3%)
26-35	4(25%)
36-45	1(6.3%)
46-55	6(37.5%)
56-65	4(25%)
>65	0

Mother's Age: M=75.7 Range = 53-92 N = 12

Mother's Residence:

Same Community	= 3(25%)
Other Communities in State	= 4(33.3%)
Out-of-State	= 5(41.7%)

Mother's Living Arrangements:

Own home or apt. with spouse	= 7(58.3%)
Own home or apt., alone	= 2(16.7%)
With me	= 1(6.3%)
Nursing home	= 0
With other relative	= 1(6.3%)
Own home with full-time care	= 1(6.3%)

Father's Age: M=76.9 Range = 58-96 N= 11

Father's Residence:

Same Community	= 5(45.5%)
Other Communities in State	= 3(27.3%)
Out-of-State	= 3(27.3%)

Father's Living Arrangements:

Own home or apt. with spouse	= 7(63.6%)
Own home or apt., alone	= 0
With me	= 3(27.3%)
Nursing home	= 1(9.1%)
With other relative	= 0
Own home with full-time care	= 0

Number of Surviving Parents:

Both Parents	= 7
Mother Only	= 5
Father Only	= 4

Table 3 -- Comparisons of Pre-Post Scores and of Difference Scores

Items from Burden Interview (7-point scale where 1="not at all", and 7= "extremely")	Pre and Post Scores for All Subjects After Wkshop			Comparison of Difference Scores between Exp. & Control Groups*		
	Pre (N=32)	Post (N=32)	Sig.	Exp.Grp. Diff. (N=16)	Ctrl.Grp. Diff. (N=16)	Sig.
It's painful to watch my parent age	4.8	4.9	n.s.	0	.19	n.s.
I feel useful in my interactions with my parent. (R)	4.8	5.1	n.s.	.44	-.25	p<10
I feel that my parent makes requests which I perceive to be over and above what s/he needs	2.0	2.4	n.s.	-.25	-.62	n.s.
I feel stressed between trying to give to my parent as well as to other family responsi-bilities, job, etc.	3.6	3.3	n.s.	.5	-.31	n.s.
I feel that I don't do as much for my parent as I could or should.	3.6	3.3	n.s	.69	-.81	p<.05
I feel pleased about my interactions with my parent. (R)	4.5	4.8	n.s.	.56	-.12	n.s.
I am afraid of what the future holds for my parent.	4.4	4.5	n.s.	.5	-.25	n.s.
I feel my parent is dependent.	3.8	3.8	n.s.	0	-.38	n.s.
Because of my involvement with my parent, I don't have enough time for myself.	1.9	2.2	n.s.	-.44	-.12	n.s.

*Positive difference indicates movement in a positive or desirable direction on a given item. Negative difference indicates movement in an undesirable direction. Signs have been reversed for the three positively phrased items (R) to be consistent with other items.

I feel resentful of other relatives who could but do not do things for my parent.	2.6	2.6	n.s.	.31	.19	n.s.
I feel that I am contributing to the well-being of my parent.(R)	4.9	4.9	n.s.	.50	-.44	p<.05
I feel that my parent doesn't appreciate what I do for him/her as much as I would like.	2.2	2.2	n.s.	0	-.12	n.s.
I feel angry about my interactions with my parent.	2.1	2.2	n.s.	-.12	0	n.s.
I feel that I would like to be able to provide more money to support my parent than I am able to now.	2.5	2.9	n.s.	-.19	-.06	n.s.
I feel that my parent seems to expect me to take care of him/her as if I were the only one s/he could depend on.	2.4	2.3	n.s.	-.06	.06	n.s.
I wish that my parent and I had a better relationship.	3.1	3.3	n.s.	-.31	-.38	n.s.
I feel nervous or depressed about my interactions with my parent.	3.2	3.0	n.s.	-.38	0	n.s.
I feel guilty about my interactions with my parent.	3.0	2.7	n.s.	.38	.38	n.s.
I feel that in the past, I haven't done as much for my parent as I could have or should have.	3.2	3.4	n.s.	-.12	-.56	n.s.
I feel that my parent tries to manipulate me.	3.3	2.7	p<.05	.62	-.5	p<.05
TOTAL BURDEN SCORE	61.55	60.87	n.s.	2.62	-4.12	p=.112

Table 4: Mean Evaluations of Workshop Effectiveness
(on 7-point scale, where 1="not at all", and 7="very much")

	Group 1	Group 2	Combined
As a result of this workshop, I feel I now have new ways of relating to my parent.	4.9	5.1	5.0
As a result of this workshop, I feel more capable of helping my parent make use of community resources.	5.8	5.8	5.8
As a result of this workshop, I feel I have more information to help my aging parent make decisions.	4.6	5.6	5.2
As a result of this workshop, I feel more capable of setting realistic limits in my relationship with my parent.	4.9	4.9	4.9
As a result of this workshop, I feel more confident that I can help my aging parent.	5.2	5.3	5.3
I feel that I have achieved the main goal I had for this workshop.	5.8	5.5	5.6

Table 5: Participants' Ratings of Workshops

Participants responded using the following ratings:

1=Very High
2=High
3=Average
4=Low
5=Very Low

Items	Group 1 Mean	Group 2 Mean	Combined Mean
Overall quality of the program:	1.5	1.7	1.6
Quality of the instruction:	1.5	1.7	1.6
Quality of supporting materials (handouts, videotapes):	1.3	1.5	1.4
Quality of arrangements for physical comfort:	2.3*	1.8*	2.0
My desire to attend a more advanced workshop on this topic:	2.1	2.3	2.2

*These ratings reflect the fact that the workshop was originally scheduled in a room that was not large enough for the group. The room was changed half-way through the first workshop. The entire second workshop was in the larger room.

Participants' responses to the question, "What did you find most useful about this workshop?"

Category	Number of Participants Who Mentioned It*
Sharing experiences, ideas, suggestions with others	18
Information on community resources	11
Information on aging process	10
Book, handouts, videotapes	9
Learning ways to improve relationship with parents	4
Diversity of topics and instructors' backgrounds	3

*(From 32 post-questionnaires)